

## **Data Needs for Evaluation of Injury Prevention Programs – Experiences From Sweden**

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### **Abstract**

Evaluation of injury prevention programs demands data from different sources. This includes data about input and exposure of preventive activities, and the influence on knowledge, attitudes and behavior of the population and to injuries as such. In this paper we will emphasize the measurement methods and validity problems of injury surveillance.

Sweden by tradition has good access to register data with good quality. Since 1951, Swedish cause-of-death statistics have been collected and classified according to ICD with few coding errors and missing data. A national hospital discharge register was established in 1964, including injury data with a low drop-out rate.

The National Injury Prevention Program starting 1986 promotes local injury out-patient registration activities. Almost every county council has been monitoring injuries, but mostly for parts of the counties covering one or more hospital areas. There is a great variation in the level of missing data and a lack of studies on reliability and validity.

Surveys including a few injury-related questions are performed both at local, regional and national level.

Information about injuries is collected at different levels in the health care systems. By tradition and technical reasons these different data are stored and analyzed apart from each other. By linking the injury cases of the causes of death, the hospital discharge and the local out-patient registers more comprehensive injury patterns can be described. The surveys cannot be linked to the registers due to lack of a civil registration number.

The about 5,000 fatal and 160,000 hospital-treated in-patients with injuries are coded according to the external causes of morbidity and mortality (E-number) of the ICD classification.

The current challenge is the possibility of getting national representative information of the about 800,000 injuries treated in out-patient care by physicians. The NOMESCO classification of injuries is used in almost all local out-patient registrations, and has shown to be the most applicable data collection instrument.

### **Data Needs for Evaluation of Injury Prevention Programs – Experiences from Sweden**

The strategy of the Swedish Injury Prevention Program stress the responsibility for injury prevention in different sectors in the community and at the national level [1]. Prevention may focus on the individuals in order to change behavior and attitudes, but also on the environment by supervision and legislation.

Preventive activities are performed at different levels and with different messages aimed to influence the individual behavior or the environment. Models can be used to show the relationship between these structures.

Preventive work is mainly based on two dimensions – the primary target levels, and the nature of the message (Figure 1). At one extreme the message can be of the single-factor type and aimed at the individual, e.g., "use bicycle helmet". At the other extreme, the National Institute of Public Health may work on prevention on the national level. Such an intervention may consist of a lot of varying things – legislation, guidelines for advertising, information, etc. Between these extremes you may find a multi-factor accident and injury prevention program on the local community level—a "community intervention"—or perhaps accident prevention work within a business firm—an organizational intervention. The general nature of the message will differ substantially for each of these examples because of different focus.

The model in Figure 1 is used as a base for another model (Figure 2) [2, 3]. This second model is developed in connection with an evaluation of a cancer prevention project in Stockholm County. A third dimension is now added—individual/environmental conditions. The individuals risk are affected by knowledge, attitudes and practice/behavior (KAP), and related to norms in the society or in the groups/organizations to which the individual belongs. The environmental condition consists of the physical local environment, safety equipments, but also the laws, policies, supervision, etc. and the sociopolitical structure.

When influence of preventive activities is discussed a fourth dimension has to be considered—intervention components/links. The input of intervention creates or modifies activities that determine the level of exposure. This affects the individuals knowledge, attitudes and behavior, and hopefully decrease the risk for injury, and in turn reduce injury morbidity/mortality. This logical chain of events serves as a point of departure for a discussion of problems with evaluating injury preventive work.

In Figure 3, the different components in this chain of events have all been assigned their own box—all with their specific, and in certain respects, general measurement problems to discuss [3].

In this paper we will emphasize the injury surveillance and the validity problems (the box to the right). A more complete discussion of all these boxes and the evaluation problems are presented in the proceedings from a conference about Child Safety in Sweden 1987 [4].

The presentation will be divided in three parts—the demographic data (as a denominator and for linkage), survey data on injury and mortality/morbidity data. Available data sources are described with comments on validity problems.

## **Demographic Data**

Demographic data can be used as a denominator, for linkage to injury registers to add valuable information.

### Population Statistics in Sweden

Population statistics for the counties and municipalities of Sweden are published in an annual report—Population Statistics [5]. The population reports are based on the Register of the Total Population (RTB) kept by the National Central Bureau of Statistics (SCB or Statistics Sweden). Every person living in Sweden has a unique civil registration number, which is used as an identifier. The vital statistics are based on the notifications of births, deaths, migrations etc., which the RTB obtains each week from the Tax Authorities. Between 1686 and July 1, 1991, the local work was a task for the Church of Sweden and was carried out by the parish offices.

The County Councils update their own population registers every second week. These registers are used for linkage to health care data registers to add information about address and check for correct civil registration numbers. The local registers for use in the health care systems are updated about every month with data from the County Councils.

The quality of the population register is considered to be good. Births and deaths cause very small under- and over-coverage problems. Undercounting is less than 0.1 percent for newborns and children under one year of age. Immigration causes some under-coverage because the time-lag between entry in Sweden and population registration is generally about four months. Emigration causes over-coverage because the population register is not always informed about departures. At the time of the 1985 Census the over-coverage was 0.1 percent of the population.

### Population and Housing Census

Sweden has a long-standing tradition of population censuses, the first being performed as early as 1749. The importance of the censuses as population counts has now decreased, and the principal significance is instead as the only national source about household, occupation and housing conditions. Since 1960 the Swedish population and housing censuses (FoB) have been combined in one census carried out every fifth year [6].

The value of the census was questioned before the latest performance 1990. The census was strongly supported by the Swedish epidemiologists and new censuses are supposed to be performed in the future. The information was at the latest census collected to November 1, 1990 by using questionnaires and by adding information by linkage to administrative records (SCB RTB, Register of Employment, Central register of Enterprises and Establishments, register on income-tax).

The census 1990 has been validated by a random sample of 17,000 persons, included in a special working craft investigation where different variables have been checked against the census. The classification quality is good, e.g., the marriage/consensual union groups with 1.3 percent is not correctly classified in the census 1990.

## **Survey Data on Injury**

### National Survey of Living Conditions

The National Surveys of Living Conditions (ULF) studies started 1974 with a sample of 11 – 14,000 persons from the whole of Sweden in the ages 16–74 year [7]. The data are collected by interviews. From 1980 the sample also includes persons 75–84 and reduced to a sample of 7–9,000 each year. In the analysis two years is used as a basis. From 1988 also people above 85 are included.

ULF contains questions about health and social data especially from 1981–82 and 1988–89 and every year from 1975 a question about long term disease or a consequence of an injury within the latest 12 months. A follow-up question about type of problem and if an injury coding by ICD9 is done. According to this definition of an injury about 4 percent of the population had such injury in the ULF studies from 1988/89.

The drop-out rate is between 14 to 20 percent. The influence of the interviewer has to be considered.

### Community (Regional/Local) Surveys

Regional or local population surveys have been conducted in many Counties during the last decade. Some of these surveys include questions about injuries.

In Stockholm County population surveys are performed every third year as a basis for a public health report and for preventive purposes. The latest surveys are conducted 1993, one survey for the adults and one performed in school classes in the ages 11,13 and 15 year.

## **Injury Mortality and Morbidity Data**

### Cause of Death Register

Swedish data on causes of death have been collected on a national basis since 1749. For the period 1831–1910, however, the collected data are incomplete and include only selected causes of death.

Since 1951, Swedish cause-of-death statistics have been collected, classified, and edited according to the International Classification of Diseases (ICD). The ninth revision of the ICD was implemented in 1987 [8].

Before July 1, 1991 a death certificate including information about the cause of death, had to be issued by a qualified physician within a week. The certificate was sent to the local parish offices and forwarded to the Statistics Sweden (SCB). From July 1, 1991 the death certificate is divided in two parts: a certificate and a cause-of-death statement. The death certificate must be issued and sent to the local Tax Authorities within a week. Within three weeks a cause-of-death statement has to be sent to SCB. At SCB, the cause-of-death statements are recorded in an annual cause-of-death register, which also includes demographic variables copied from the Register of the

Total Population (RTB). The register is used to produce the official statistical tabulations, but is also available for medical research. The register now contains information on individual deaths from 1952 to 1991.

The County Administrations register of reported death (which do not include the cause of death) is used to check the cause-of-death register for comprehensiveness. For the data of year 1991, SCB was unable to obtain death certificates in 356 cases.

The death certificates are coded at SCB. The underlying cause of death is selected manually and validated by the ACMIE program (supplied by the National Center for Health Statistics, North Carolina). A validity study 1986 of 5300 death certificates by an independent control coding procedure showed a coding error of 3.6 percent on the 3-digit-level and 1.4 percent on the chapter level. In 1990 the underlying cause of death was studied in 2195 certificates by independent coding: on the 4-digit-level 4.4 percent of coding errors occurred, 3.0 percent on 3-digit-level and 0.7 percent on ICD chapter level. The validity is dependent on the age and the cause of death, e.g. injury is among the more valid causes of death.

The fatal injuries are about 5,000 per year in Sweden. About 93 percents of the diagnoses are at present based on autopsy result or diagnostic procedures at hospital.

A limitation according to the injury field is that the place of injury is not registered. There are ongoing discussions within the nordic countries to add the place of occurrence and a free text description of an injury event.

#### "Cases of Death" Register

The Cases of Death Register is handled by Statistics Sweden and is based on a record linkage of Causes of Death 1961-70 and the Population Census (FoB) 1960. The foremost value is in the more valid occupational information.

A new record linkage has been done with the Causes of Death 1971-80 and FoB 1970. Some data from the register have been analyzed, but no report have been published so far. The general use of the cases of death register have decreased in the latest years, and the check of the civil registration numbers were time consuming. By now ad hoc record linkage is used when special questions arise and someone will pay for the analysis.

#### The National Hospital Discharge Register

To provide data on in-patient utilization to researchers, planners and decision makers a National Hospital Discharge was established within the National Board of Health and Welfare in 1964, with data from parts of the country. The register is based on the local County Council registers. From 1978 to 1983 data are available from 18 out of 26 County Councils (about 85 percent of the population), 1984 is lacking, but from 1985 all public hospitals in Sweden are participating.

The variables included are diagnoses, surgical procedures, external causes to injury or poisoning, date for admission and discharge. For the period 1964-83 also civil registration number. From November 1, 1993 the County Councils, according to a new legislation, are obliged to deliver data with a civil registration number. Registration numbers from the period 1985-93 may be added.

The number of discharges per year is about 1.7 million, of which 160,000 are due injuries. Missing data on discharges were estimated to 2 percent in a study 1989. A study of the 1986 year register has shown that the medical information on the detailed 5-digit-level has major classification errors, about 17 percent, but with moderate problems (7 percent) when data are grouped in DRG or when using the Nordic 99-diagnosis list [9]. The injury data, however, have less errors, about 7 percent on 5-digit-level.

The E-code on 4-digit-level show totally 22 percent errors, of which 14 percent were due to a use of a wrong E-code.

#### Local Trauma Registers

A few hospitals in Sweden have started trauma register, e.g., Lund University Hospital in 1993 [10]. The information is used for quality assurance and evaluation of the trauma care. The data are compiled from the ambulance and the emergency records and in-patient care.

### Out-Patient Register

The Centre of Epidemiology at the National Board of Health and Welfare has initiated a National Out-patient Register with a content corresponding to the Hospital Discharge Register. The register, based on data from the local level, has gradually been established for the out-patient hospital care, with about half of the County Councils participating at present. Information from the primary health care is limited to a few County Councils. The medical information—consisting of diagnosis and external causes of injury or poisoning (E-code)—is increasing, but still insufficient. Personal identification is lacking in the central register. A complete register from the whole of Sweden would provide information of an estimated total amount of about 800,000 annual injuries in Sweden, treated by physicians and not admitted to hospitals or being lethal.

### Local Surveillance Systems

Almost every County Council has registered injuries during the last decade. According to a survey in April 1993 about 50 percent had an ongoing injury surveillance system. But, these registration activities are limited in some respects. In most of the Counties not all hospitals are involved in the registration. Some registrations focus on special groups and areas, e.g. child injuries, school injuries and traffic injuries. Considering these limitations about 25 percent of the Swedish population is covered by an injury surveillance system.

The data collecting is based on the Swedish version of the NOMESCO Classification [11, 12]. This classification is multi-axial, each axis describing the site of occurrence, the mechanism of injury and the activity of the victim. There is also a possibility for a detailed free-text description of the injury event.

Besides the information about the patient (civil registration number, age, sex, place of residence, etc.) the main axes of the NOMESCO classification above are mainly on the 1-digit-level, the supplementary situation code, the date of injury and the diagnosis are to be considered as a minimum data set.

Registration of more detailed or extended variables mirrors local interests in special preventive areas. Examples of these are sport and traffic injuries, injuries among children or the elderly, at institutions etc.

The amount of missing data shows a great variation from 5 percent to 50 percent, but the most frequent amount is about 5–10 percent. No studies have been performed on the quality of the coding procedure.

### Traffic Injuries

Police is required to complete a report on all road traffic accidents with personal injury. These reports are compiled and analyzed by Statistics Sweden. Police reports include comprehensive information about the conditions relevant for the cause of the accident as well as personal identification.

Different studies have shown a significant under-reporting of these data [13, 14].

### Occupational Injuries

Swedish legislation requires employers to report all occupational injuries causing sick leave to the local Social Insurance Office. Copies of these reports are sent to the labor inspectorate and Swedish Occupational Injury Information System (ISA), administered by the National Board of Occupational Safety and Health. The purpose of the register is prevention of accidents. The register includes information about the injured person, the employer, the work situation, extent of the injuries, and a description of the injury event.

There is a significant under-reporting of the occupational injury data, shown in different studies [15, 16].

### The Insurance Companies Injury Registers

The insurance companies collect different kinds of data about different types of injuries. Among others there are information related to occupational, traffic, sport and leisure-time injuries. However, the information is not stored as databases with possibility to make tabulations.

### **Community and National Injury Information Systems**

The different sources for describing the injury problem and for evaluating the outcome of preventive activities have been presented above. The data generated by the public health care system provides the most comprehensive information on injuries because no injury type is excluded.

The focus at the national level has up to now been on fatal or in-patient hospital discharge injuries, which are the most severe. However, this gives a limited picture of the problem. Most of the injuries are treated in out-patient care with different types of injuries sustained in different sectors of the society. For example about 75 percent of the injuries occur in homes or during leisure time.

The National Injury Prevention Program in Sweden [17] starting 1986 have promoted local injury out-patient registration activities, now covering about 1/4 of the Swedish population, which could be used on the national level, compiled to a national out-patient register.

The local surveillance systems cover patients treated in emergency departments and in many cases within primary health care. This includes patients treated only in out-patient care, as well as those admitted to hospital in-patient care and those with fatal outcome. By tradition and technical reasons this information is stored and analyzed apart from the other sources of information on injuries. By linking the injury cases of the causes of death, the discharge and the local out-patient registers more comprehensive injury pattern can be described. The purpose is to validate and to add useful data. The NOMESCO classification of accident monitoring is, with almost no exception, used in the local surveillance systems—including when a registration of intentional injuries are performed—and has shown to be the most applicable data collection instrument. The classification gives possibilities to collect the information on different levels of details. For the performance and evaluation of preventive efforts on the local level the data have to be more detailed.

The first step in the process to establish a national surveillance system is to link information from the Cause of Death Register to the Hospital Discharge Register. This is possible by the civic registration numbers which are now also available in the Hospital Discharge Register. Such a performance has been initiated by the Centre for Epidemiology at the National Board of Health and Welfare.

The next step—to include data information from the local surveillance systems—needs a permission to collect personal identification data, which according to an ongoing legislative process might be possible from 1996.

This comprehensive model with general information on injuries—within the framework of a minimum data set—including data from all sectors and all types of injuries provides a useful foundation to define national policies and to measure if targets have been achieved.

The data needs of the national agencies responsible for injury prevention in different sectors (e.g., consumer, traffic, occupational, child or elderly safety) are to some extent fulfilled by the minimum data set. Detailed information have to be provided (at cost) in cooperation with a few County Councils. A possible linkage may be performed to other data sources, such as the police reported traffic injuries and the occupational injuries.

The present trends concerning the local surveillance systems are towards a continuous registration by a minimum data set. Time limited projects that focus on special areas of interest can be made by expanding to a higher level of detail or by using the supplementary parts in the NOMESCO classification, e.g., the traffic module or the external injury factor/product module. Further supplements are in progress.

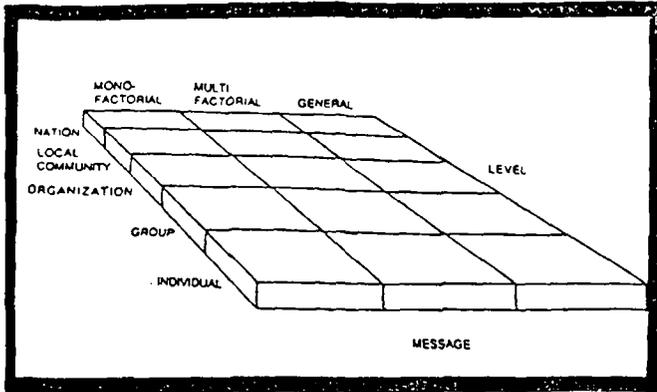
The most urgent problem is to improve the validity of the local systems, with less under-coverage and misclassifications and to improve the geographical representation. The role of the Centre for Epidemiology is to facilitate that work, to collect and analyze representative national data, and to coordinate the work with the national agencies and the County Councils.

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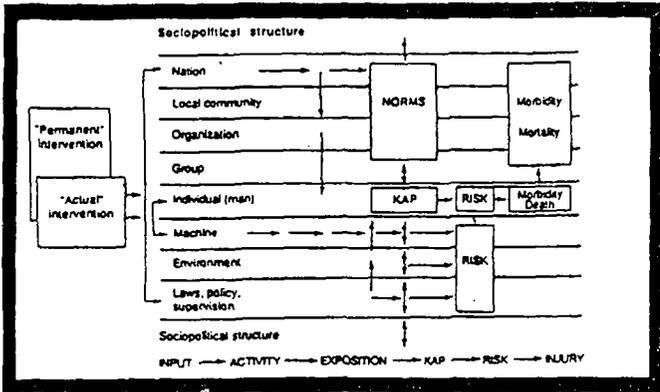
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**Figure 1. Preventive work - level/message**



**Figure 2. Intervention/level/risk/injury**



**Figure 3. Possible study designs at evaluation of intervention programs.**

